

Talking Points for CDC Conference on Medicaid Data Sharing

- ◆ Sometimes political/personal issues can get in the way of a sensible plan
- ◆ Single largest issue we had to overcome was an often icy relationship between the two agencies – interagency relationships downright embarrassing
- ◆ Fortunate in that we enjoyed support from the leadership – information is a product, not a possession attitude
- ◆ Also fortunate that both agencies had a stake in reaching a solution – we wanted each others data
- ◆ To get around personal issues, tried to delegate some “ambassadors” with no history, worked on building personal relationships by working on separate non-contentious issues together
- ◆ At times felt more like international shuttle diplomacy than actual epidemiology...
- ◆ There were also some legitimate concerns that needed addressing: Issues of legal authority and confidentiality, staff work loads in producing the data, appropriate use of the data, avoiding public embarrassment by publishing incorrect results, etc
- ◆ Solution to both legitimate concerns and issues of mistrust between the players: a painfully detailed written agreement
- ◆ Took over seven months to get to a signed agreement– it addresses:
 - ◆ Legal issues – documents the relevant statutes protecting confidentiality and the statutes outlining each agencies responsibilities that dictate the need for the data
 - ◆ Confidentiality – documents the expectations of both departments in terms of keeping information secure and in terms of to what level of detail summary information can be released
 - ◆ Turf – requires that the data only be used for specific purposes outlined in the document
 - ◆ Trust/Accuracy/Communications – establishes a “Lead Data Use Workgroup” with equal representation from both departments (Discussed, but eventually got beyond dictating a coin toss from a neutral party to decide who chairs workgroup...). Workgroup will meet at least quarterly to “enforce” and interpret the agreement – also all “results” one agency obtains from the other’s data must be reviewed by the workgroup prior to any sort of dissemination for technical accuracy.
- ◆ Despite the wrangling, we managed to keep lawyers out of the generation of the document – had council of both departments review final negotiated version.